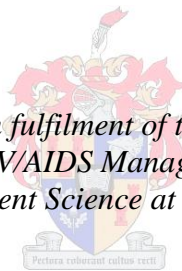


**AN INVESTIGATION INTO THE WAYS IN WHICH LEADERS OF  
KRAAIFONTEIN ADDRESS HIV AND AIDS AND HOW THIS COULD  
INFLUENCE THE LEVELS OF HIV-RELATED STIGMA IN THE COMMUNITY**

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*Assignment presented in fulfilment of the requirements for the degree of  
Master of Philosophy (HIV/AIDS Management) in the Faculty of Economic  
and Management Science at Stellenbosch University*



Supervisor: Ms Caroline Wills  
April 2014

## **DECLARATION**

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

February 2014

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## **ACKNOWLEDGEMENT**

My sincere gratitude goes to my supervisor Ms Caroline Wills for the guidance that she gave throughout the research. It would not have been possible also without the support of friends and family especially my husband Jacob Kufa and the kids.

A big thank you to my mother in law for being there for the children during that time and to my late mum for the support you gave, I can imagine how you would have ululated at this.

I would also want to thank all leaders in Kraaifontein who supported me during this research.

Finally to all Mphil students, thank you so much. Thank you to the staff members of Africa Centre for HIV/AIDS Management. Thank you, Professor Jan du Toit.

## **ABSTRACT**

This research is an investigation of how leaders in Kraaifontein area address HIV and AIDS and how this influences the levels of stigma and discrimination amongst the community members. A research was carried out in the Kraaifontein area using a mixed approach. Fifteen leaders were identified using purposive sampling method whilst their followers were randomly selected. A thematic analysis was done to determine the levels of stigma amongst leaders. Questionnaires were distributed to the community members to be able to measure the level of stigma and discrimination. Data which was collected from interviews was summarised in a report. Each leader was assigned to a code from A to O. The community members' questionnaires were also labelled A to O corresponding to their Leaders. This was done to enable a comparison of reports between leaders and their subordinates or followers. The research established that though there are low levels of enacted stigma in Kraaifontein according to the results, there were shockingly high percentages (57%) of people who believed that HIV and AIDS is a punishment for bad behaviour. Seventy-one percent believed that it's a punishment from God whilst 86% would not buy from someone with AIDS. The research showed that although people have the knowledge on how HIV virus is spread, there still remains an element of sigma and discrimination. Further recommendations were also made for future studies.

## OPSOMMING

Hierdie navorsing is n ondersoek oor hoe leiers in kraaifontein area HIV en VIGS adresseer en hoe dit verband hou met hulle volgeling. N markpeiling was uitgevoer in die Kraaifontein area met gemengde gevoelens.<sup>15</sup> Leiers was geïdentifiseer dat hulle gebruik maak van doelbewuste toetsing terwyl die volgeling na willekeur gekies is. n Tema analise was gedoen om te bepaal hoe hoog die stigma onder leiers was. Vraelyste was versprei onder lede van die gemeenskap om te bepaal op watter vlak die stigma van diskriminasie was. Data was verhaal van onderhoude en opgesom in n verslag. Elke leier was n kode toegeken van A tot O. Die gemeenskapslede vraestelle was ook geïntekeneer van A tot O oorkomstig hulle leiers. Hierdie was gedoen om te vergelyk verslae tussen leiers en ondergeskikte volgeling. Die navorsing het bevind dat alhoewel daar lae vlakke van voorskryf stigma in Kraaifontein is ooreenkomstig die verslae daar skokkende hoe persentasie van mense (57%) glo dat HIV en Vigs n straf is vir hul swak gedrag. 71 % glo dat dit n straf van God is en 86% sal niks koop van mense met Vigs. Die navorsing het getoon dat alhoewel mense die kennis het oor hoe HIV virusse versprei, daar steeds n element of stigma is. Verdere aanbevelings was gedoen vir toekomstige studies.

## ACRONYMS

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>ARV</b>	Antiretroviral
<b>ART</b>	Antiretroviral Therapy
<b>HCT</b>	HIV Counselling and Testing
<b>HIV</b>	Human Immunodeficiency Virus
<b>NGO</b>	Non-Governmental Organisation
<b>PLHIV</b>	Person/ People Living With HIV
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNESCO</b>	United Nations Educational, Scientific and Cultural Organization
<b>USAID</b>	United States Agency for International Development
<b>WCC</b>	The World Council Of Churches

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## CHAPTER 1: BACKGROUND AND RATIONALE

People Living with HIV (PLHIV) have often been stigmatised and in Sub Saharan Africa which carries a burden of 69% HIV, it is a challenge UNAIDS (2012). The Oxford Dictionary defines stigma as, “a mark of disgrace associated with a particular circumstance, quality, or person.” Goffman (1963, p.3) describes stigma as an act that will cause someone to be reduced and discounted.

Leadership involves influencing individuals to achieve a common goal. Northouse's (2007, p.3). A leader has people that follow him and he/she influences them to do certain acts, usually people believe what the leader believes in and they work towards achieving their leader's goal. The way leadership address HIV issues is an important aspect to be understood because it could affect the way followers do. This research was to identify if there is HIV-related stigma amongst leaders as well as community members in Kraaifontein in the Western Cape in South Africa.

Stigma remains a big challenge towards effectively responding to HIV. HIV-related stigma is complicated because of pre-existing stigma such as those relating to sexuality, gender, race and poverty (Goffman, 1963).

The effects of stigma on PLHIV and those at risk of HIV infection are quite intense. It causes people not to go for HIV Counselling and Testing (HCT) as well as accessing services for prevention and care (Boer and Emons, 2008) as people may fear stigma from family and friends and thus fail to disclose. Whilst antiretroviral programmes are scaling up, (Coetzee, Hildebrand, Boule, Maartens, Louis, Labatala, 2004, p. 887-95) there is need to address stigma so that it becomes effective. Stigma can lead to discrimination, which can include hostile behaviours. When stigma becomes enacted then this becomes discrimination. There are a number of ways people have been discriminated in the past. They are times when people have been banned from going to church because they had AIDS. One of the most extreme examples is that of Gugu Dlamini's who was stoned by neighbours near Durban in South Africa when she spoke openly on World AIDS Day in 1998 ([www.aegis.org](http://www.aegis.org)).

According to Gilmore and Somerville (1994, p. 4) stigma is a process and is identified in the following four steps:

- 1) It starts as a label – when someone is ill or just the HIV test result. When someone gets an HIV-positive result, he/she begins to label him/herself with the disease. At times the community can label someone if they think that an individual who is ill and who has symptoms related to AIDS. There are also situations whereby someone attends support groups or health caregivers visit and people label that person as HIV positive.
- 2) Target group – When people assume that you are ill because of certain symptoms such as weight loss. The community and individuals also relate certain symptoms to AIDS and thus when one has those symptoms he/she becomes a target.
- 3) Label of disgrace – As the sickness progresses people begin to show discrimination. At times people look at those that will be affected and they put blame on the one who is sick.
- 4) Response to the stigma – At this stage the one who has the disease begins to respond to the way people view him/her. The person with the disease feels people are distancing him/her and at times it is him/herself who distances from others in the society. This is known as internal stigma.

Leaders have different ways of addressing HIV issues. “HIV can give a social mark of disgrace to a person” (Greeff, Phetlhu, Makoae, 2008, p. 311-320). Most of the time the way leaders view things cannot be separated from that of their subordinates. How people look at HIV issues may cause stigma. In addressing stigma and discrimination, making use of those in leadership could be helpful if they are anti-stigma as their knowledge and sometimes attitudes influence the people they lead. Leaders have influence that can change a community. It is important to know why leaders address HIV issues the way they do because this can have implications on the levels of stigma and discrimination.

### **Research Question**

How do the leaders in Kraaifontein address HIV and how does it influence the levels of HIV-related stigma in the community?

### **Significance of Research**

The community at large could benefit from this research. This research evaluates leaders and their followers in Kraaifontein and the way they address HIV. The community could benefit from this research as the problem of HIV-related stigma will be highlighted and how stigma

can be reduced will be discussed. The community could benefit from ways which will be recommended to reduce HIV-related stigma in Kraaifontein.

### **Aim**

To establish how leaders address HIV and AIDS in Kraaifontein and explore what effect this has on levels of HIV-related stigma in the community.

### **Research Objectives**

1. To assess the attitudes of leaders towards HIV in Kraaifontein.
2. To identify the different strategies that leaders implement in order to reduce HIV-related stigma.
3. To measure HIV-related stigma in the Kraaifontein community.
4. To make recommendations about how leaders in Kraaifontein can effectively address HIV-related stigma.

### **Structure of Research Report**

Chapter 1: This chapter gives a brief background of the research, aim and the objectives of the study.

Chapter 2: A thorough review of related literature is found in this chapter. Information from the chapter is mainly from what other scholars believe and also what is on the ground.

Chapter 3: The focus is on the research methods used. The research used the mixed method approach which is explained in this chapter and how it was used to investigate stigma and discrimination amongst leaders and their followers. How the data was analysed and managed is also explained as well as data quality and ethical issues.

Chapter 4: Research results which were collected are explained with the aid of tables and figures. The data is analysed in this chapter giving special attention to the objectives of the research.

Chapter 5: The discussion of research findings presented in the previous chapter is found in this chapter.

Chapter 6: This closing chapter presents the conclusion of the research. Recommendations are made for future studies.

## **CHAPTER 2: LITERATURE REVIEW**

### **Sources of Stigma**

HIV and AIDS is often associated with pre-existing stigma that is caused by the following factors.

### **Sex and Sexuality**

Unprotected sex is one of the ways that HIV is transmitted. Often times, especially in Sub Saharan Africa this is associated with unacceptable behaviour when it is associated with; homosexuality, promiscuity, sex work, and pre or extra marital affairs. Since HIV was discovered, it was believed that the blame was on homosexuals for bringing the HIV virus and thus many people did not like them in society (Parker et al,2000). Sex is often perceived to be for those who are married especially in the African context. Often times people are afraid or shy to be known that they engage in sexual activities when they are not married. On the other hand also once someone is married people expect them not to indulge in extra-marital affairs. Therefore premarital and extra marital sex especially for women is very discrediting and agrees to Hoffman's definition of stigma.

### **Gender**

Women failed to acquire the education men got because often times they have been disadvantaged because of culture . According to Aggleton and Warwick (1999) this makes them more vulnerable to HIV. Women also have fewer economic advantages. Therefore they are more vulnerable which means that they may look for ways of getting money or goods by entering into relationships that may lead to unwanted sex. Most of the times women get to know their HIV status when they go for antenatal clinic and when they disclose they are blamed for bringing HIV into the home. In the African tradition women are expected to behave well and be submissive even if they discover their husband is cheating they cannot deny sex. It is also an African belief that people must not easily give up on marriage, and these are the challenges that women face every day. Those expectations that the community have for women are the causes of pre-existing stigma because if they fail to do what they are expected to, then they are labelled by the community.

According to studies, many men do not want to have protected sex especially when they are paying for it. In other areas also people believe that a man cannot 'stick' to one sexual partner

so in this instance men are blamed. The Health Minister Dr Aaron Motsoaledi was quoted by the *Sowetan* “It is clear that it is not young boys who are sleeping with these girls. It is old men. We must take a stand against 'sugar daddies' because they are destroying our children,” (Mail and Guardian, 4 March 2012). It is the older men who are actually having young girls as partners. Sometimes they use force or situations like the need for money makes them vulnerable.

### **Race and Ethnicity**

In Africa, HIV is mostly linked to Africans’ sexual behaviours such as the culture of polygamy and men having more than one partner. Aggleton and Warwick (1999). According to (UNESCO, 2002) “Gender and marital relations are some of the factors which have increases the spread of HIV and AIDS on African societies.”

### **Class**

Poverty plays a role in reinforcing HIV and AIDS-related stigma. There are certain classes of people which have always been there caused by joblessness, homelessness even before HIV was discovered. These factors which are very much aligned to poverty cause people to be exposed to acts that may lead them to contract the HIV virus. This is because when people have difficulty in accessing what they want through employment, they turn to other forms of accessing money, such as the providing sex for money.

### **Manifestation of HIV-related Stigma**

HIV and AIDS-related stigma which has different forms also manifests at different levels which are societal, community and individual (UNAIDS, 2000).

### **Society Level**

Legislation can sometimes be a source of stigma. Whilst law is supposed to protect the general public sometimes it exposes others and becomes stigmatising. Foreigners have been deported in the past when HIV positive status was discovered. (Malcolm et al. 1998:347-370). A mark is created by virtue of being deported thus separating the individual from others. In 2009, UNAIDS commissioned an team with the task on HIV-related travel restrictions internationally. They discovered that 59 countries had HIV-specific restrictions on travel. Forty-four countries were discovered to have a restriction on travel until January 2013 (UNAIDS, 2013). These restrictions are acts of discrimination for PLHIV and one can

imagine how difficult it will be to deal with stigma at community level if it stems from the top like these situations.

Programmes which are aimed at reducing the spread of HIV have been used in the past and at times, they may be a source of stigma when certain terminology is used. An example is when people are grouped and are chosen for a specific programme; this act can separate the people from the rest of world. There are projects that are to assist PLHIV, once people are recruited, everyone becomes aware of their status and it becomes labelled as a “project for the PLHIV” thus giving them a mark.

The church needs transformation to bring hope to the people (WCC,2001), Religious institutions are not exempted in addressing stigma because of past experiences of religious leaders being judgemental on PLHIV. Addressing stigma and discrimination at leadership level could be the most appropriate starting point for dealing with it in the church.

### **Community Level**

People who stigmatise against PLHIV often see it as a punishment for doing wrong. For example, they may have a way of identifying those that are taking ARVs. In the Shona Culture, people often refer to those that are on treatment as “vari pachirongwa” which means they are on ‘the’ programme. This usually happens for the unmarried people because culture does not allow sex before marriage or out of marriage. In reality this cultural belief is not adhered to because there continue to be new HIV infections amongst people at a very tender age before they are married.

It was supposed to be obvious for the family to provide support for PLHIV but in the past family has abandoned their family member after the person tests HIV-positive. This may lead to a person being socially isolated. (Parker, R.G, et al, 2000). Stigma and discrimination can also take certain forms with certain groups of people in the community, an example is the gay community where reports have been made in the past of people who experienced stigma (Brady, M, 2011). There are also other groups like women discussed under gender above who can also be discriminated against at community level. Stigma can be very hostile and can cause people to behave in unexpected ways. The often told story of Gugu Dhlamini of 1998 who was stoned in South Africa after speaking about her HIV status is an example.

## **Individual Level**

When someone is living in a community and/ or family environment where HIV-related stigma is high, fear manifests. They become socially disconnected and at times feel that they are outcasts. Lack of support from family causes people to commit suicide (Gilmore and Somerville, 1994), whilst some in the past have failed to access services and support because of fear. This undermines prevention strategies such as care and support programmes which are in place but few people access them.

People may also not disclose their HIV status to partners and relatives due to internalised stigma. When people don't disclose their status they may spread the virus to their partners and also it will result in non-adherence to ART. When stigma exists, the laws that are there to protect people are overlooked. An example is an experience of stigma at a local clinic, although all clinics will be under the same law, if the staffs have an element of stigma and the community is not well informed they will suffer because sometimes people don't know their rights.

## **The Impact of HIV and AIDS-related Stigma**

Disease-related stigma started long before HIV with other diseases such as cholera. Is someone had cholera people concluded that he/she was lazy (Duffy J, 1990 p. 797-805). However when people got to know about the germ involved in the cause of cholera through teachings, they began to accept it. The same opportunity to inform people about HIV exists. Whilst there has been some improvement in addressing HIV and AIDS-related stigma, more still needs to be done concerning stigma. People need to be educated on knowing their rights, and they also need to be taught on how stigma and discrimination manifests. The media has also played a big role in educating people about HIV they could also at the same scale talk about stigma and discrimination to raise awareness.

Quite a number of different initiatives have been used to prevent the spread of HIV for example use of condoms, training, awareness campaigns and others. However according to Robin LM,et al, 2012, it is very difficult to realise the benefit of these initiatives when dealing with a stigmatised community. Many people have not gone for an HIV test because of fear Valdiserri et al (1999). In South Africa more than 20 million people had gone for testing since HCT was introduced in 2009 (Khumalo, 2012), however there are still some people who haven't gone for testing. This could be attributed to the fear of testing HIV



positive. When someone does not know his/her status, the chances of infecting others are high if that person is HIV positive. When someone knows his/her status it helps in that for someone who tests HIV negative will receive counselling on staying negative whilst those that are positive will receive counselling and if need be, get ARVs to boost their immune system.

### **The Role of Leadership in Influencing the Response to HIV and AIDS**

Leadership role in responding to HIV and AIDS must be understood because a leader is someone who has got followers. People often look up to the business leaders, police force, religious leaders and managers of public companies. Once someone holds a title in the community, there is a tendency for people to want to imitate them.

Brass (1984) discusses how transformational leaders can influence their followers. Transformational leaders are able to change the way people see and interpret things. A leader who is stigmatising is likely to have followers that are also stigmatising.

The other dimension is those who have intellectual stimulation. They challenge the way people think and will also encourage his followers to do the same. The world needs types of leaders that can view HIV in a way that does not promote stigma. The problem with HIV and AIDS is that people think death and problems when they hear about the disease.

The third type are those that are good at their performance and often give good advice with very effective management style. According to Brass (1984), their performance is usually very high. Transformational leaders help when there is need to bring change.

In the HIV and AIDS era, it is useful to understand the type of leaders that we have. Influential people at any level in the society can help bring change to the Nation, even in this time when stigma and discrimination are a problem.

### **Overview of Kraaifontein Community**

Kraaifontein is a suburb in Cape Town located in the Northern area of the city. It has approximately 154 000 people. According to the 2011 census published by the city of Cape Town, the community has approximately 67 000 blacks, 62 000 coloured, 22 000 white and the rest Indian/Asian or other. There are 185 companies and organisations in Kraaifontein (<http://www.mbendi.com>). With restructuring in the 1990s Bloekombos and Wallacedene also became part of Kraaifontein. It is a well-established community with mainly residential areas and also some industrial sites. The people who reside go to other areas to work whilst those that work in the community work in farms and industries.

## **CHAPTER 3: RESEARCH DESIGN AND METHODS**

A mixed method research design was implemented in this research, using both qualitative and quantitative research designs.

### **Sample Size and Strategy**

This evaluation had two target groups; leaders and the community members of Kraaifontein.

#### **Leaders:**

There are approximately 185 companies and organisations in Kraaifontein (<http://www.mbendi.com>). A total of 15 leaders (8%) were selected for interviews to find out their views and attitudes towards HIV and AIDS. Purposive sampling was used to identify the leaders that were interviewed. The inclusion criteria to select leaders to participate in the research were as follows:

- Types of leaders: A range of leaders representing different types of organisations were selected. Leaders represented; religious leaders, community leaders, key business people and also managers of businesses. To qualify as a leader, the person had to represent the top management of an organisation.
- Location: Leaders were drawn from the different parts of Kraaifontein which are, Windsor Park, Scottsville, Peerless Park, Eikendal, Belmont Park, Wallacedene and Bloekombos.
- Diversity: Leaders of different nationalities, race, genders, and religion were included.

#### **Community members:**

Adult community members were randomly selected from the 15 organisations whose leaders were also interviewed. This enabled the triangulation of the data. According to O'Donoghue and Punch (2003), triangulation is the use of different methods to conduct a research and it allows cross checking or validation of results thus increasing the quality of results. The HIV status of the respondents was not required as this research was to establish the levels of HIV-stigma for the community in general. Ten people from each organisation who provided their consent to participate were selected for the purpose of the research. A total of 150 community members therefore participated in the research.

## **Data Collection Methods and Processes**

A review of literature was conducted in order to determine the sources of HIV-related stigma, how stigma manifests and what impact it can have across different institutions.

### **Leaders:**

The leaders were interviewed using semi-structured interview guides with open ended questions which were prepared based on the desired research objectives (Appendix 1). The interviews were recorded on a dictaphone whilst some were recorded on paper taking note of the important answers given, and according to key themes that emerge. The interviews aimed at establishing the levels of HIV-related stigma against six indicators which were also used for the community members (Stangl. A, Brady. L. Fritz. K, 2012).

- a. Fear of infection
- b. Social judgement
- c. Anticipated stigma
- d. Perceived stigma
- e. Experienced stigma
- f. Discrimination

### **Community members:**

Questionnaires (See Appendix 2) were for ten adults per selected organisation. The questions were grouped into six sections to determine the indicators of stigma in the following ways (Stangl. A, Brady. L. Fritz. K, 2012):

- a. Fear of infection
- b. Social judgement
- c. Anticipated stigma
- d. Perceived stigma
- e. Experienced stigma
- f. Discrimination

## **Successes and Constraints during Data Collection**

Data collection was a cumbersome process, because not all of the people initially approached were cooperative. In order to secure ten participants from an organisation, the researcher had to have 15 people as a backup. Some people chose not to return the questionnaires, and some leaders were very difficult to set an appointment with as they were always busy. Some leaders refused for their interview to be recorded so there was a need to write notes whilst

they were talking. For most interviews, the participants expressed that they had difficulties discussing HIV-related issues, and anticipated the interview to be very difficult. The comment people always gave after the interview was “is that all, I thought it was going to be very difficult.” This shows a lack of confidence that leaders have in discussing HIV and AIDS issues. This could further be attributed to the way leaders are so reluctant to speak about HIV and AIDS to their community as established by the research.

### **Data Management**

Data which was collected from interviews was summarised in a report. Each leader was assigned to a code from A to O. The community members' questionnaires were also labelled A to O corresponding to their Leaders. This was done to enable a comparison of reports between leaders and their subordinates or followers.

### **Data Analysis**

#### **Leaders:**

The researcher conducted a thematic analysis to understand the views of leaders in Kraaifontein. Leaders' responses were then compared to one another in order to determine whether their responses were similar or different.

Furthermore, the data analysis determined whether the response by the community members is related to the response of their leaders.

#### **Community members:**

Information collected from the questionnaires was entered into Excel and analysed quantitatively answering the following questions:

- 1) Percentage of people who fear casual transmission and refusal of contact with PLHIV
- 2) Percentage of people who indicate shame, blame and judgment for PLHIV
- 3) Percentage of people who indicate enacted stigma (discrimination)
- 4) Percentage of people who have difficulty in disclosure of their HIV status.

### **Assumptions**

- It was assumed that leadership had direct influence on the attitudes of their followers.
- It was assumed years spent in leadership would not impact negatively on the research; therefore time spent in a leadership position was not an issue.

- It was assumed that all leaders would give honest answers not regarding their status quo.
- It was assumed that the leader's level of education would not affect their ability to lead a group.

### **Data Quality and Ethics**

- 1) Purposive sampling ensured that a broad range of perspectives be included in the research.
- 2) The researcher consulted with her supervisor particularly during the design and initial planning of the research to identify relevant variables, issues, and stakeholders.
- 3) Data collection tools were semi-structured. Findings were gathered through note taking by the interviewer and some recorded for back-up purposes.
- 4) During data analysis 'triangulation' between various sources and kinds of data was used.
- 5) Informed consent: The code of ethics and conduct of Stellenbosch University was adhered to. Willing participants were informed of the aims of the research and they provided their consent to participate by signing a consent form (Appendix 3).
- 6) Conduct of Research: Interviews were conducted in a preferred place with the use of recordings. Participants participated voluntarily and some declined to answer some of the questions during the interview. No comments were linked to any names to protect their anonymity.
- 7) Feedback: Respondents were given permission to contact the researcher for feedback on the research and also allowed to see their recorded responses before they were compiled into a report if they wanted to make any corrections. All respondents were told about the recordings and promised that they will be kept in a safe place.
- 8) Data Storage: The data which was recorded from the interviews was transferred to a CD and is in a lockable place. The questionnaires which were filled in are also in a safe place away from reach of other people.

## **CHAPTER 4: RESEARCH FINDINGS AND ANALYSIS**

Outcomes from questionnaires which were completed by community members from organisations were labelled A to O. The other part addresses the findings from Leaders A to O using the qualitative analysis approach. A comparison between Organisation A and its leader A and so on was also done. A general analysis was done for the whole community on the quantitative data as well as the qualitative data so as to establish the general level of response to stigma in the Kraaifontein community.

### **Outcomes from Questionnaires**

A total number of 150 community members who were randomly selected took part in the research by responding to questionnaires (Appendix 2). The questionnaire was structured to provide information on

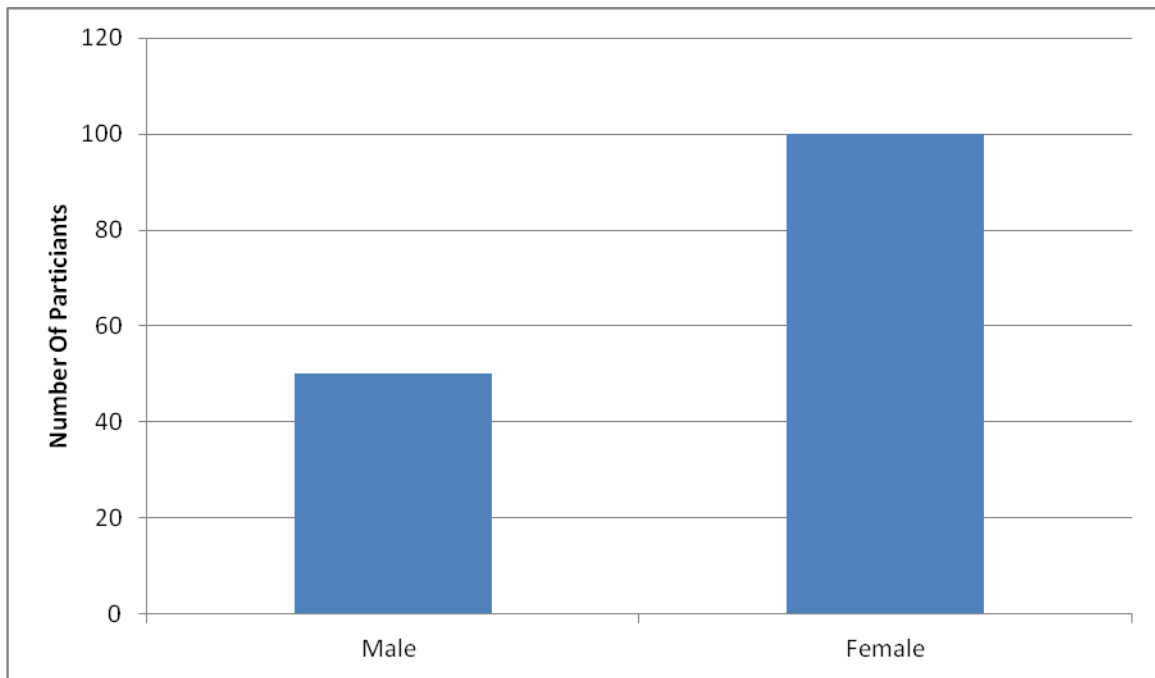
- a. Biography
- b. Fear of infection
- c. Social judgement
- d. Anticipated stigma
- e. Perceived stigma
- f. Experienced stigma
- g. Discrimination

### **Biographical Information**

The biographical description of the people who took part in the research is represented in the figures below:

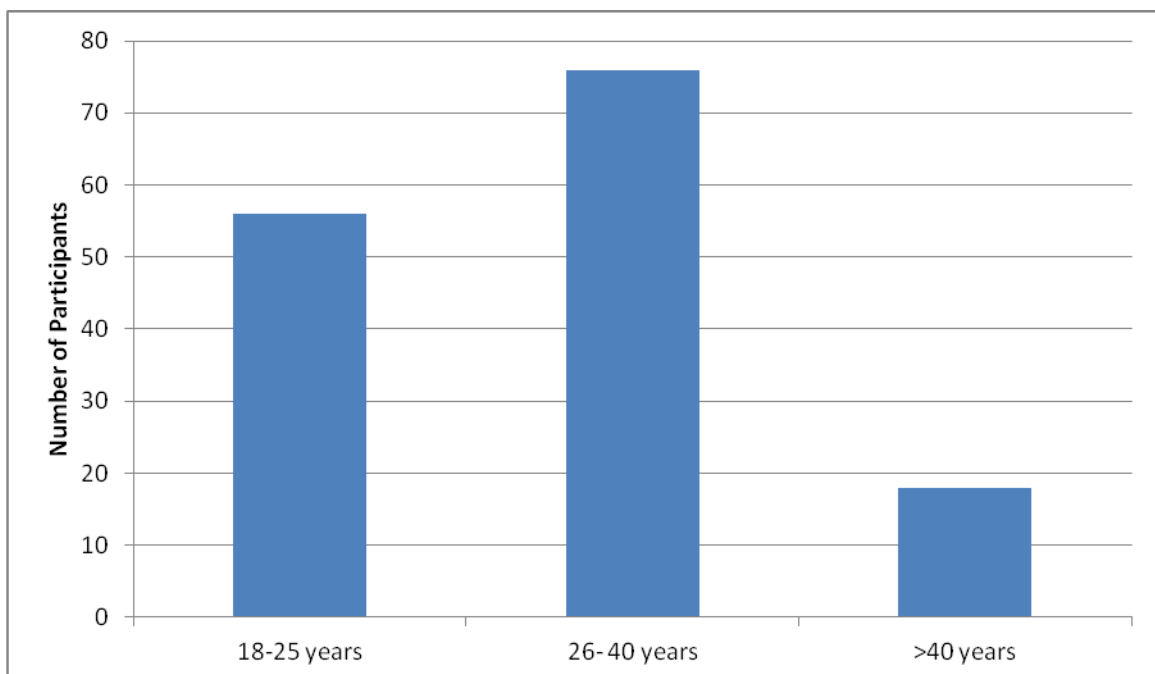
**Figure 1- Gender Distribution of Community members**

One hundred female compared to fifty male community members took part in the research.



**Figure 2 - Age distribution of Community Members**

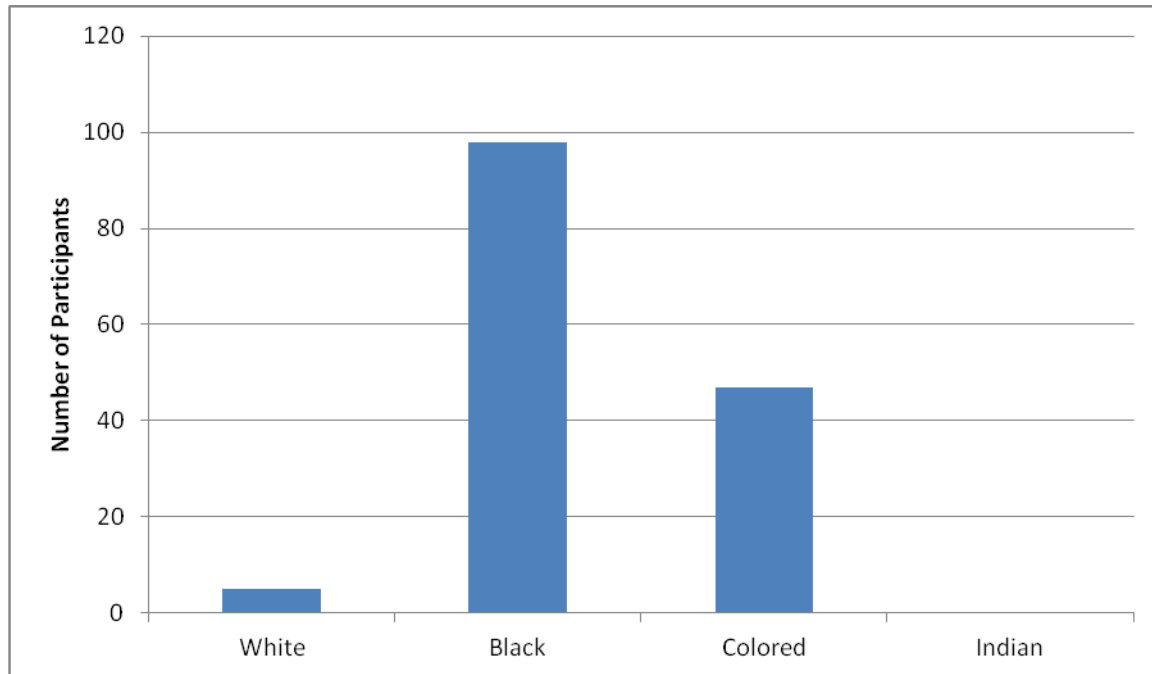
As shown in the figure below, age distribution was from 18years to more than 40years. Fifty-six members were between 18-25years, seventy-six were between the range of 26-40 years whilst eighteen were above 40years of age.





**Figure 3- Distribution of race for Community Members**

There were 5 white people who took part in the research for the community members. Ninety-eight were black whilst forty-seven were colored. No indian community member took part in the research. The information is shown in the figure below:



The biographical information was collected and recorded just to show variation of participants who took part. The data was not used for further analysis to establish the results or make any conclusions of the research.

Further questions were grouped into four sections for analysis. The responses were recorded and below are the responses:

### **Section 1 : Indication of fear and refusal of contact with PLHIV**

This section was designed to test the respondents for fear and refusal of contact with people infected with HIV. As seen in Table 1 below, on average the overall reflection was that 81% did not reflect fear and refusal whilst almost 17% showed that they would not contact people with the infection. About 2% were not sure of how they would react. Respondents seemed to understand how HIV is transmitted and were not afraid to contact PLHIV. However, there are 86% of the respondents who indicated that they are still not comfortable to buy food from those visibly sick though they are aware that they will not contract the HIV virus. This response indicates some level of discrimination amongst the people in the community especially that this response came from the majority of the respondents.

**Table 1 - Responses to determine fear and refusal to contact people with HIV and AIDS**

		% Yes	% No	% Do not know
1.	I could become infected with HIV if you are exposed to the saliva of a person living with HIV		100	
2.	I could become infected with HIV if I were exposed to the sweat of a person living with HIV		100	
3.	My child could become infected with HIV if they play with a child living with HIV		100	
4.	I could become infected with HIV if I were to provide physical care for a person living with HIV		100	
6a	In a market of several food vendors, would you buy food from a person living with or suspected of living with HIV who was not visibly sick?	86	14	
6b	And what if they were visibly sick?	14	72	14

**Section 2 : Indication of shame, blame and judgement towards PLHIV**

This section addressed shame, blame and judgemental attitudes towards PLHIV amongst the respondents. On average 29% agreed to the statements that resembled shame, blame and judgement. Seventy-one percent showed that they would not be ashamed or judgemental to PLHIV. On analysis the 29% came mainly from the question on punishment given by God, of which 42% of the respondents agreed to. Whilst people may not feel shame and blame there remains an element of judging PLHIV. People continue to experience ill treatment from their relatives and partners because they believe that they deserve the punishment. Fifty-eight percent of the respondents had the perception that HIV and AIDS is a punishment for doing bad.

**Table 2 - Responses to show agreement or disagreement to shame, blame and judgement**

		% Agree	% Disagree
1.	HIV is a punishment from God	42	58
2.	HIV and AIDS is a punishment for bad behaviour	58	42
3.	It is female sex workers who spread HIV in the community		100
4.	People living with HIV are promiscuous	14	86

	How do you think most people in your community would answer the previous questions?	% Agree	% Disagree
1	HIV is a punishment from God	71	29
2	HIV and AIDS is a punishment for bad behaviour	57	43
3	It is female sex workers who spread HIV in the community	43	57
4	People living with HIV are promiscuous	29	71

	Do you agree/disagree with the following statement:	Agree	Disagree
1.	I would be ashamed if I were infected with HIV	29	71
2.	I would be ashamed if someone in my family had HIV		100
3.	People with HIV should be ashamed of themselves		100

	How do you think most people in your community would answer the previous questions?	Agree	Disagree
4.	I would be ashamed if I were infected with HIV	29	71
5.	I would be ashamed if someone in my family had HIV		100
6.	People with HIV should be ashamed of themselves		100

**Section 3 : Indication of enacted stigma/discrimination**

This section helped to establish any enacted stigma people had experienced in the past. About 27% on average indicated that they had witnessed any enacted stigma in the past. As seen in Table 3, the predominant form of stigma was through gossip.

However overallly 73% indicated they had not witnessed much enacted stigma. Stigma and discrimination may be in existence in Kraaifontein though it may not have developed to enacted stigma.

**Table 3 - Responses to determine the indication of enacted stigma or discrimination**

	Do you know someone in the past year who has had the following happen to him/ her because of HIV or AIDS?	% Yes	% No
1.	Excluded from a social gathering	42	58
2.	Lost customers to buy his/her produce/goods or lost a job	14	86
3.	Had property taken away	14	86
4.	Abandoned by spouse/partner	14	86
5.	Abandoned by family/sent away to the village	28	72
6.	Teased or sworn at	14	86
7.	Lost respect/standing within the family and/or community	28	72
8.	Gossiped about	72	28
9.	No longer visited, or visited less frequently by family and friends	28	72
10.	Visitors increase to “check them out.”	28	72
11.	Isolated within the household	14	86

#### **Section 4: Indication of difficulty in disclosing HIV status**

This Section was designed to test for ease of disclosure, and 57% (85 respondents) failed to complete this section of the questionnaire. However of the 65 that completed it, only 14% (9 respondents) indicated that people in the community would often get to know about someone’s status when they disclose their own status. Fifty-eight percent knew people who in the previous 12 months had disclosed their HIV status. Respondents were not given an opportunity to comment on why they had left the section open as it had been stated to them that they had an option not to answer where they were not comfortable.

**Table 4 - Indication of difficulty in disclosing HIV status**

Are there people you personally know who have either disclosed their HIV-positive status directly to you or publicly in the last 12 months? For example, a family member, friend, neighbour, church member, or work colleague.		
1	Yes	58%

2	No	42%
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In your community, what are the primary ways that people know if someone has HIV?  
(Tick your choice)

1.	The person discloses his/her status.	14%
2.	From general rumours/gossip.	42%
3.	From the HIV-positive person's family.	0
4.	From the HIV-positive person's employer.	0
5.	From the HIV-positive person's friends/neighbours.	42%
6.	From the health centre/health care worker where the person got tested.	0
7.	The person looks ill and has lost a lot of weight.	42%
8.	Other (specify).....	

### Outcomes from interviews.

A total number of 15 leaders were interviewed and they were either recorded by Dictaphone or by writing down notes. The interviews were done to establish the level of stigma against six indicators

- a. Biography
- b. Fear of infection
- c. Social judgement
- d. Anticipated stigma
- e. Perceived stigma
- f. Experienced stigma
- g. Discrimination

These indicators were in turn used to determine whether the way the leaders responded to HIV and AIDS was linked to the way the workers viewed HIV and AIDS.

#### Leader A

This leader represented a religious organisation. He indicated that he was aware of HIV and AIDS though he had not really taught people about it. He said “we often teach people how bad sexual immorality is.” The knowledge that he had was not from any training that he had attended but from news and experiences. He however indicated that HIV and AIDS wasn’t a good thing to be associated with Christians because it indicated some weaknesses and would draw people away from the church especially if it is one of the Leaders affected.

#### Leader B

Leader B was from a local public facility. Employees at the company had previously received some teaching on HIV and AIDS according to the policy of the company. He however indicated that the training had not helped much. He said “the training that we have will be override by the benefits that people get for having unprotected sex like giving people grants for having a child.” He indicated this point so strongly and said that he didn’t care about people who die of HIV and AIDS. He mentioned that people who had the disease were to blame for their irresponsible behaviour.

#### Leader C

From a local manufacturing private company, this leader was also the owner of the company who indicated that he understood the subject of HIV and AIDS. At one point he had invited trainers to train the workers on the subject. He explained that there was still need to have more training for people especially on the subject of stigma and fear. He felt that people still lack knowledge and he strongly emphasised the point of dealing with stigma and discrimination. He had not experienced it personally in the company but suspected it could be a problem.

#### Leader D

Leader D was from a religious organisation and he indicated that he had knowledge about HIV and AIDS that he had acquired from news and experiences. He mentioned that stigma and discrimination remained a challenge in the church because it is mainly associated with sexual immorality which is viewed as one of the worst sins. He however said that he would not judge people because of their HIV status though he also said, “I wish this disease can just find a cure.” He had not given any lessons to his members in the past on HIV and AIDS as they operate under the guidelines of the doctrine of the church which focuses on the second

coming of the Messiah. Their focus is on saving people's lives from spiritual death. This leader had his views which he could have dealt with had it not been he is operating under a big organisation and has to comply.

#### Leader E

This leader is a local business person with a busy beer hall in the location has quite a number of people who report submit to her. She has also built a lodge with rest rooms where people come from different areas to book a night or more. She mentioned that people blamed her in the area for promoting prostitution. She had knowledge about HIV and AIDS from the news and what she had seen in the community. She had never discussed HIV and AIDS with the people around her. She believed that HIV and AIDS is just like any other disease and could be controlled using the medication that is available. She said people should not be afraid at all as death will always come everyone is destined to die one day.

#### Leader F

This leader leads an upcoming Non-Governmental Organisation (NGO) in the community which assists children with money to acquire basic education. They also assist adults with start-up capital for their businesses. She indicated that the employees had not received any education from the NGO on HIV and AIDS. She said that HIV and AIDS is a problem for everyone and people must not stigmatise or discriminate others.

#### Leader G

Service station manager, leader G also shared his view on HIV and AIDS indicating that it was a problem for all. He said "I will never tell people if I get that disease because they will talk about me especially as their manager" He however felt that people should not discriminate one another as they do not know how it shall be with them in life. However, one imagine having such a leader who finds it hard to disclose his HIV positive status, it would be very hard for others to disclose also in this case.

#### Leader H

Also from a service station, this leader had some knowledge on HIV and AIDS which he had received from a training some time ago. He also mentioned that stigma was a problem though he would not mind disclosing his HIV status.

#### Leader I

This leader, from a tyre service company, had little knowledge about HIV and AIDS. He said “I am aware there is a disease called AIDS but I haven’t really looked into the details but I know it’s caused by sex.” He indicated that it was not good to discriminate others but thought it was a self-inflicted disease. Though he felt that it was not good to discriminate, his language was very much stigmatising and he showed that he was uninformed on issues of transmission.

#### Leader J

A small retail shop leader also indicated that HIV and AIDS had resulted in many deaths in the country and it affected the industry. He however indicated that stigma still remains a problem because people lack knowledge despite all the teachings on television. He disagreed that anyone could be blamed for having the disease just like any other disease.

#### Leader K

From one of the giant retail shops, this leader indicated that training within the company had helped so much to curb stigma and discrimination. She mentioned that people were now relaxed and did not fear HIV and AIDS like before. She would not mind disclosing her HIV status. This shows the impact of educating people and how it helps to empower PLHIV.

#### Leader L

Leader L from a vegetable shop also showed an understanding on HIV and AIDS though she had not gone for any training before. She indicated that it was difficult to live openly with HIV as people will just talk about you. She also said that the problem was that it has to do with sexual immorality which most people regard as a sin. She was not sure how she would take it if she ever discovered that she was HIV positive.

#### Leader M

Also from a small retailer, leader M showed an understanding of the causes of HIV and AIDS and was aware of stigma. He however was not comfortable in disclosing his status and he had never gone for an HIV test.

#### Leader N



This leader did not want to talk much about HIV and AIDS but he mentioned that he had heard about it. He showed an element of fear of the disease and had not witnessed discrimination. This leader had a private sewing company and also a retail shop.

#### Leader O

Leader O from an upcoming NGO was happy to share his experiences. He mentioned that he had stayed with his own parents who were HIV-positive and had seen how people had stigmatised them. He was happy to have the subject of stigma being discussed to help people as in his experience HIV-related stigma really exists. He was not afraid to disclose his HIV status.

### **Analysis of the Link between Interviews and Questionnaires**

Leaders and community members expressed their different opinions with regards to HIV and AIDS which gave an insight of stigma levels in Kraaifontein. An analysis was also done to see if the responses by the community were in any way related to their Leaders' responses.

It was difficult to directly compare the attitudes of community members to their leaders most of the time, at times they would have common views but the same people on another point would differ. For example you would find that a community member is full of fear of casual transmission yet they didn't indicate shame and judgement for PLHIV which maybe the Leader would be doing. Of the 15 leaders who were interviewed only two leaders B and L shared the exact view as more than 50% of their subordinates. Whilst leaders may have different views from their followers at some point, the overall view showed that the stigma levels amongst the community were almost similar to those of the leaders. Issue of disclosure is one other area where there was an indication of similar responses.

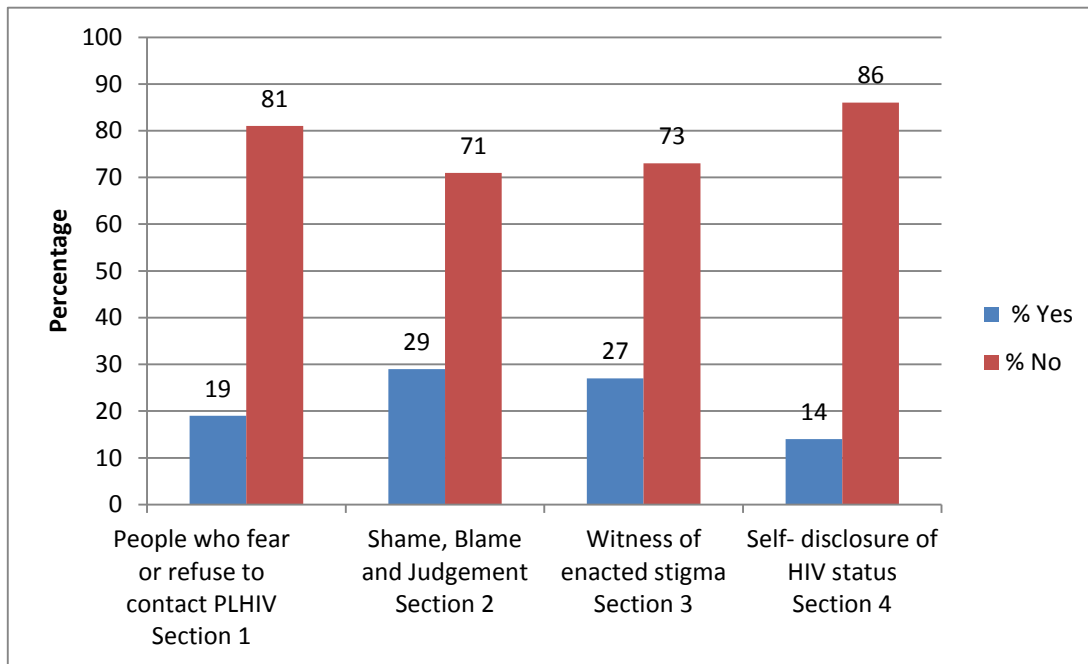
## CHAPTER 5: DISCUSSION OF THE RESEARCH FINDINGS

The discussion is divided into sections. Qualitative and quantitative data was analysed separately and then a triangulation of the data was done to be able to compare how they were related.

### **Analysis of Quantitative Data**

The questionnaires which were distributed to community members were analysed against four indicators and the following results were recorded:

The data was also summarised to get an average view of what the four indicators were testing. Below is a graph (Figure 4) which shows the average responses that were given per each indicator used. The data shows that there is still an indication of stigma that exists in Kraaifontein. The blocks in blue indicate stigma and discrimination on average. Section A block is an analysis of people who resembled fear and refuse to contact PLHIV, 19% had fear whilst 81% had no fear of contact. About 29% indicated blame shame and judgement for PLHIV whilst 71% did not. Approximately 27% had witnessed enacted stigma or discrimination in the community whilst 73% had not seen happening. Section 4 block was analysed basing on how many people preferred to disclose their HIV status in the community. Of the 65 respondents who answered this section only 14% indicated that the usual way people would disclose their status would be by personal disclosure. Other respondents felt people got to know other people's HIV status by other means such as gossip, rumours, family and others on the questionnaire. On disclosure issues respondents who answered that section indicated that most of the times people do guess work and conclude that someone is HIV positive. Forty-two percent of the respondents indicated that they most people in the community know about someone's status through grapevine whilst zero would be informed by the person's relatives, this is a high indication of stigma.

**Figure 4 - Summary of Data Analysis**

### Analysis of Qualitative Data

The qualitative data collected from interviews was also analysed using the same indicators for the community members quite a number of points were also collected from the way the leaders responded. The way leaders responded also suggested something about the role of company policies in protecting people from stigma and discrimination. The responses given by the two religious leaders show that in both cases, the set up or doctrine does not allow them to teach HIV as a subject in church. The knowledge that they have is from experiences and also the media thus it will be important to look at the organisations policy makers in particular and not just leaders. There were some leaders who blamed the government for giving grants to impregnated girls, in this case it shows a leader who has failed to take responsibility but blames other people yet he is supposed to make a move to bring change. Only four leaders out of the fifteen had gone through some training on HIV and AIDS issues, their responses showed that it had helped except for one mentioned above who said it had not helped because of government intervention in helping people. Whilst training programmes have been introduced in most parts of South Africa, the mentality of the people also plays a role in how they are going to act on the information they receive.

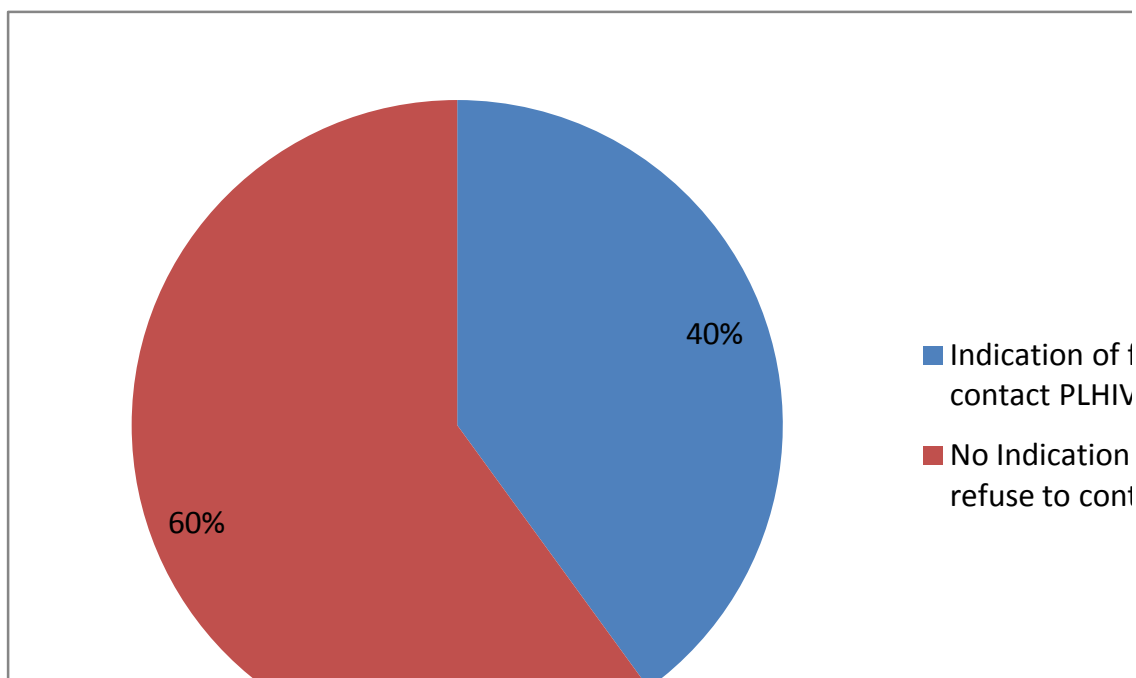
At times people are conscious of their positions and what they are supposed to say not reflecting exactly how they feel about something. Leader I is one example who said “I am

aware there is a disease called AIDS but I haven't really looked into the details but I know it's caused by sex." His tone was stigmatising yet he went on to despise and speak against stigmatising and how he wanted people to be aware yet himself didn't care. It could also be that there are certain stigmatising words which people are used to saying but not realising the impact it will have on the affected individuals. It is possible that the leader also could have just said it, it was very difficult to judge at that stage.

The findings were also put on pie charts.

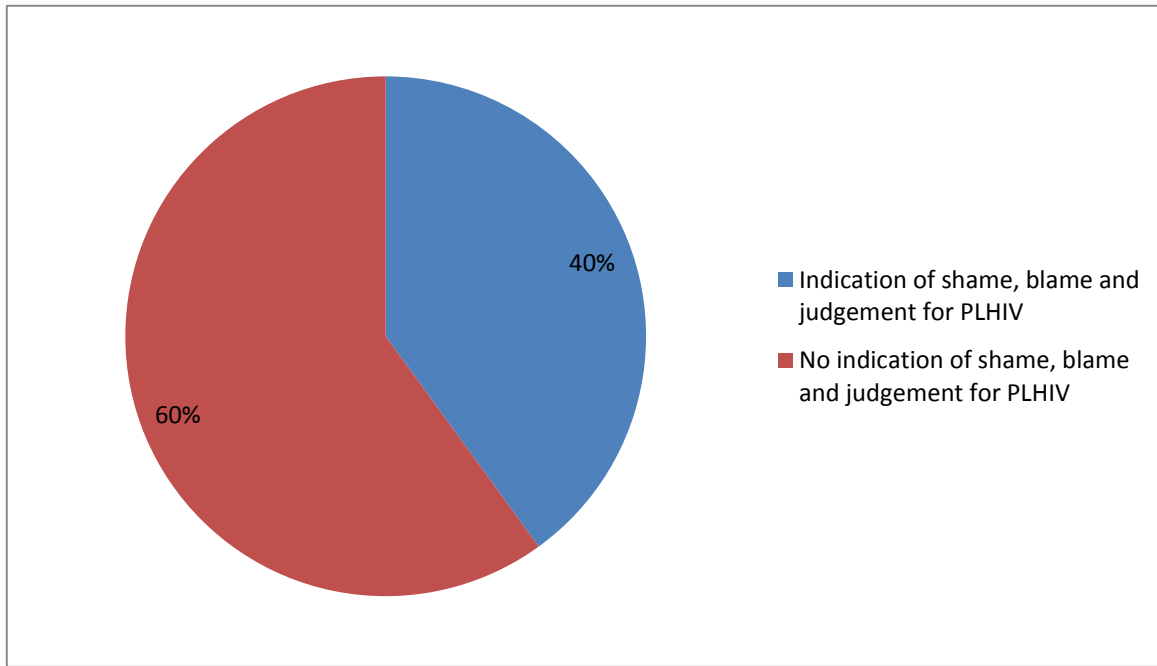
### **Figure 5: Fear and refusal to have contact with PLHIV**

The leaders were asked questions to test if they had fear to contact PLHIV. From their responses 6 out of the 15 leaders indicated fear and refusal to contact PLHIV.



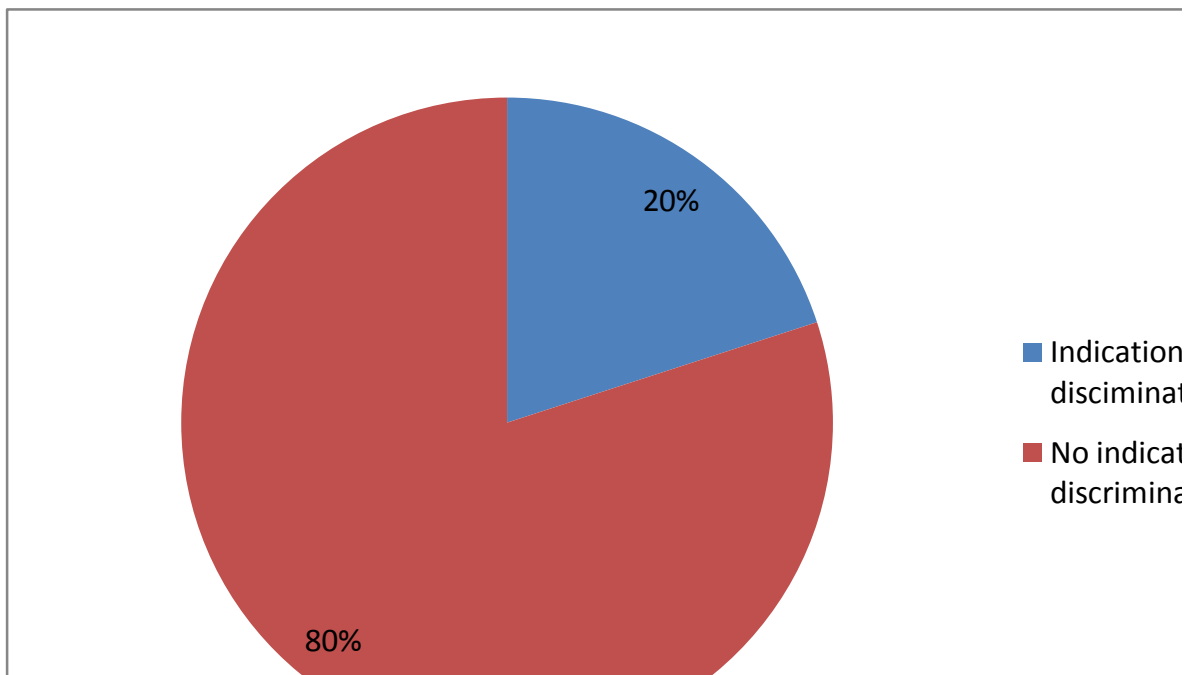
### **Figure 6 - Indication of Shame, blame and judgment of PLHIV**

Forty percent of the leaders (6) indicated shame, blame and judgement for PLHIV whilst nine of them had no indication of shame, blame and judgement.



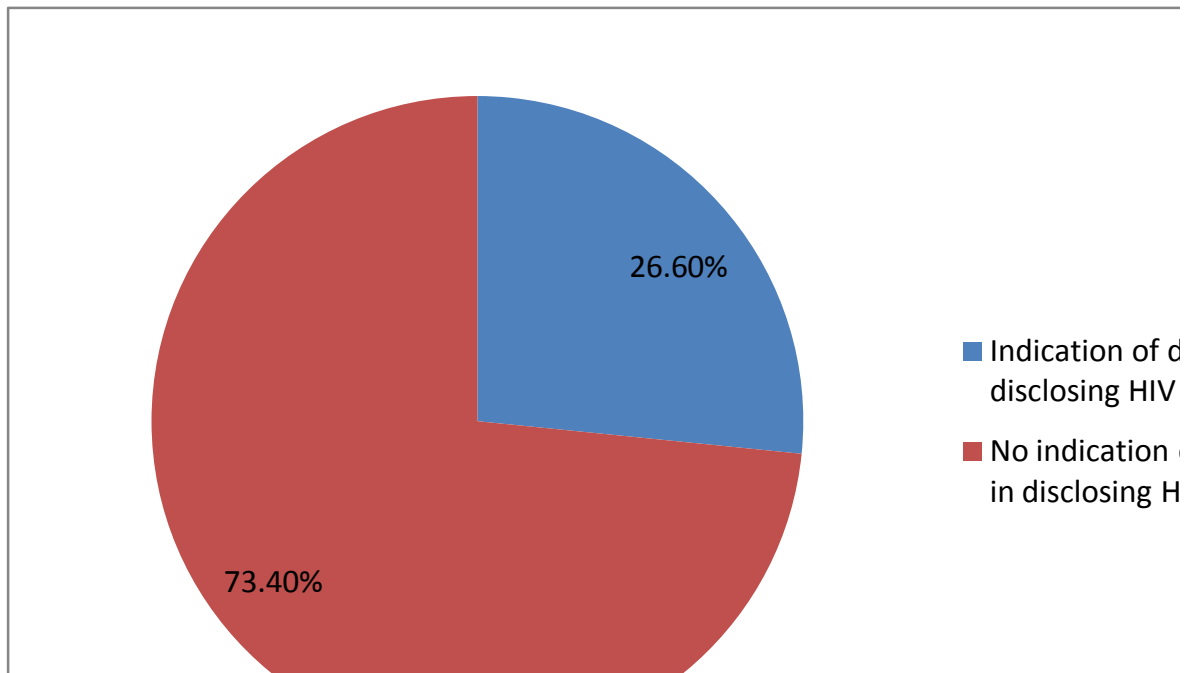
**Figure 7 - Indication of witnessing stigma and discrimination**

Three people showed that they had experiences of enacted stigma whilst twelve of them had not experienced it.



**Figure 8 - Indication of having difficulty in disclosing HIV status**

This was asked differently from the community members, for the leaders it was to test their difficulty in disclosing their HIV status whilst for the community members it was to test disclosure amongst the other members of the community. The results indicate that 4 out of 15 of the leaders would disclose their status whilst 11 out of the 15 would not disclose their HIV status to the public.



### Comparison of Qualitative and Quantitative Data

#### Indication of fear of casual transmission and refusal of contact with PLHIV.

For the leaders, 40% indicated that they had fear of casual transmission compared to 17% of the community members who also felt the same way. There are quite a few number of people who still fear casual transmission and refuse to contact PLHIV. The research revealed that people are now aware of how HIV is spread; this can be seen by the response of questions 1 to 4 in section 1. The leaders also indicated that they had the basic knowledge of HIV and AIDS transmission from the media and some had gone through proper training.

#### Indication of shame, blame and judgment for PLHIV

Forty percent of the leaders showed an element of shame, blame or judgement for PLHIV compared to 29% of the community members. Whilst there was a slight difference in response between the two groups, there are relatively low levels of shame, blame and judgement for PLHIV reported by the community. The higher percentage for leaders could

have been because of sample size involved which could maybe give a different result if more leaders were interviewed. However the community's response to section 4 which is for disclosure could also indicate that people are still ashamed of PLHIV.

### **Indication of enacted stigma (discrimination)**

Twenty percent of the leaders who were interviewed indicated stigma and of the community members 27% had witnessed enacted stigma in the community. This general indication shows there are low levels of enacted stigma in the community. Whilst there could be an existence of stigma in Kraaifontein, it cannot be easily noticed from what people experience. The level of stigma noticed in leaders is almost the same as in what the community members have witnessed.

### **Indication of difficulty in disclosure of their HIV status.**

Twenty seven percent of the leaders who were interviewed showed that they were not comfortable in disclosing their status if ever they found out they were HIV-positive. This section was not properly answered by the community members as the majority left the section unanswered. It could not be established whether it was lack of time or they avoided these questions purposely. However of those who answered only 14% indicated that people would know someone's status by personal disclosure whilst most of the options were through grapevine or gossip. It was established from both interviews and questionnaires that most people were still not comfortable in disclosing their status. The reason why people would hear information through grapevine shows also that there is lack of confidentiality in the community. There is also an element of discrimination when people discuss about someone's HIV status in private. According to Jamaican Information Service (2012), PLHIV may be stigmatised by their co-workers resulting in discriminatory practices. This could be attributed the possible reasons for people to fear disclosure.

Previous research has shown that it is easier for someone to disclose their status when they know someone who is HIV-positive (Vonneilich, et al, 2012). This can also be seen by the response of leader O who stayed with his parents who were HIV-positive. Leader O was very open and indicated that he was not afraid or ashamed to disclose his HIV status.

### **Summary of Research Findings**

The findings of the research show similarities as well as contrast between questionnaire and interview. According to the results from the questionnaire there is a low level of stigma and

discrimination in the community of Kraaifontein. The qualitative data analysis showed that the leaders were aware of stigma and discrimination and had seen it in the past. The triangulation helped to establish the aim of the research which was to establish the influence of leadership on the level of HIV-related stigma in Kraaifontein.

Leaders were reluctant to give answers during the interviews. This can also be linked to how some community members failed to fill in the forms whilst others left some questions unanswered. Most of the leaders shared the same view on HIV stigma and discrimination as the community members. Relatively the level of enacted stigma in Kraaifontein according to the respondents is low, however 86% indicated that they would not buy food from PLHIV or thought to be living with HIV though not visibly sick.

Though the respondents showed that they had knowledge about how HIV is spread they were still not comfortable in buying from infected people, however the leaders did not show that indication. The reason could have been the level of thinking of the leaders which is quite different from their subordinates. The differences in response between the leaders and community members could be attributed to their intellectual levels. Sometimes it was very difficult to link the facial expressions to what one was saying.

Subordinates shared different views some linked and others not even linked to what the leaders indicated. The research did not show any direct link of the leaders' response to those of the community members.

From the research, stigma and discrimination are evident forces that threaten the efforts aimed at halting the spread of HIV and AIDS. Though low levels of enacted stigma were detected from the research, people are still afraid to disclose their status. Fear of disclosure is also a hurdle in trying to curb the spread of HIV and AIDS, this ultimately affects the rate at which individuals decide to test. Research in the past has shown that the decision to disclose results from people weighing the advantages and disadvantages (Armistead et al, 2001). When people feel that they will experience discrimination of some sort they prefer avoiding to their HIV positive status to be known. According to Draimin 1993, disclosure may subject people to some form of rejection. Therefore the ease for disclosure of a person's HIV status is a very large indicator of stigma levels. High levels of failing to disclose openly could suggest that people are living in a community that does not enable them acceptance.



## **CHAPTER 6: CONCLUSION AND RECOMMENDATIONS**

### **Conclusion**

This research was undertaken to establish how leaders address HIV in the community and explore what effect this has on levels of HIV-related stigma in the community. The objectives were to, assess the attitudes of leaders towards HIV in Kraaifontein, identify the different strategies that leaders implement in order to reduce HIV-related stigma, measure HIV-related stigma in the Kraaifontein community and make recommendations about how leadership in Kraaifontein can effectively address HIV-related stigma.

The respondents could clearly show the understanding of the concept of stigma and discrimination in the community though they indicated low levels of enacted stigma. They were some responses which were high indicators of stigma and discrimination in the community. The issue of disclosure is an example where both leaders and community members proved not to be comfortable with it. They were also high levels of blame as community members indicated that HIV and AIDS is a punishment from God.

In line with what other researchers have done in the past, stigma and discrimination constitute the greatest barriers to dealing effectively with the HIV epidemic. The impact of stigma and discrimination as highlighted in Chapter 2 of this research report is a cause for concern. Leaders are the core people in the society and a leader is believed to have power to influence. In this regard if leaders are equipped in a certain way they can be a source of influence to the community in addressing stigma and discrimination. The media plays a vast role in spreading awareness, but it is the role of the leader to reinforce that to community members. The way leaders address HIV and AIDS could impact the way the community members responds to it. Stigma and discrimination are issues that still need to be addressed in the Kraaifontein community.

### **Recommendations**

HIV-related stigma and discrimination are complicated issues that affect individuals at different levels. The results of the research point to the existence of some elements of stigma and discrimination in the Kraaifontein community. This research has revealed, it is recommended that:

- Further research covering more organisations and leaders in the area be conducted to explore the factors that hinder people from disclosing their HIV status. Key leaders who influence very large groups of people like Religious leaders will also be considered.
- Small organisations should be made aware of the need to develop HIV and AIDS workplace policies.
- For future research, there should be involvement for PLHIV so that they speak out about HIV stigma.
- Leaders to get training on HIV and AIDS issues so that they have an understanding of the disease. In addition they should also be provided ideas on how to manage issues relating to HIV and AIDS.
- Small organisations should make an effort to develop Employee Health and Wellness Programmes addressing stigma and discrimination in the workplace.
- Organisations should be encouraged to have dedicated budgets to pay for trainings and programmes.
- The media should also speak more on stigma and discrimination and also share examples of those leaders that are exemplary on how they have managed to be transformative with regards to HIV and AIDS.

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## **APPENDIX 1: INTERVIEW SCHEDULE FOR COMMUNITY LEADERS**

1. Please introduce yourself, your position in the organisation and for how long you have been in this position.
2. How big for you think is the problem of HIV and AIDS for the community of Kraaifontein?
3. How important do you think it is for you, as a leader, to address HIV and AIDS in Kraaifontein?
4. How much education have you received about HIV and AIDS (Probe: where did you get the information from, what are the key areas that the community leader is knowledgeable about)?
5. How confident are you about speaking about HIV and AIDS (Probe: if they are confident, what gave them confidence? If they lack confidence, explore ways this could be built)?
6. What kind of HIV and AIDS education and awareness messages have you given to your community (Probe: explore the focus of the messages – how HIV is transmitted, how to treat a PLHIV)?
7. How often do you give these messages?
8. What platforms do you use to give these messages (Probe: verbal, written, one on one, families, groups?)
9. Have you/ do you know of PLHIV in Kraaifontein? (Probe: how well they know the person, what contact do they have with the person)

10. How easy do you think it is for them to live openly with HIV in Kraaifontein? Provide reasons for your answer.
11. How do the community of Kraaifontein perceive HIV (Probe: explore whether particular groups are more stigmatised – women, sex workers, migrants, refugees, people of different sexual orientations)?
12. In your opinion, are people hesitant to take an HIV test due to fear of people's reaction if the test result is HIV-positive?
13. Do people talk badly of PLHIV or people thought to be living with HIV? Explore.
14. Can you provide any example/s where PLHIV have been discriminated against?
15. What did you do in response to this? What were your thoughts?
16. What do you think are some effective strategies that you can do to reduce HIV-related stigma in Kraaifontein?

**APPENDIX 2: INTERVIEW SCHEDULE FOR COMMUNITY MEMBERS**

1.	Male			Female	
2.	Age	18-25 years	26-40 years	>40 years	
3.	Race	White	Black	Colored	Indian

**Section 1**

4. Please answer yes, no, or do not know to the following statement:

		Yes	No	Do not know
5.	I could become infected with HIV if you are exposed to the saliva of a person living with HIV			
6.	I could become infected with HIV if I were exposed to the sweat of a person living with HIV			
7.	I could become infected with HIV if I were exposed to the excreta of a person living with HIV			
8.	My child could become infected with HIV if they play with a child living with HIV			
9.	I could become infected with HIV if I were to provide physical care for a person living with HIV			
10.	In a market of several food vendors, would you buy food from a person living with or suspected of living with HIV who was not visibly sick?			
11.	And what if they were visibly sick?			

**Section 2**

5. Do you agree/disagree with the following statement:

		Agree	Disagree
5.	HIV is a punishment from God		
6.	HIV and AIDS is a punishment for bad behaviour		
7.	It is female sex workers who spread HIV in the community		
8.	People living with HIV are promiscuous		



6. How do you think most people in your community would answer the previous questions?.....  
.....

7. Do you agree/disagree with the following statement:

		Agree	Disagree
7.	I would be ashamed if I were infected with HIV		
8.	I would be ashamed if someone in my family had HIV		
9.	People with HIV should be ashamed of themselves		

8. How do you think most people in your community would answer the previous questions?  
.....  
.....

### Section 3

9. Do you know someone in the past year who has had the following happen to him/ her because of HIV or AIDS?

		Yes	No
12.	Excluded from a social gathering		
13.	Lost customers to buy his/her produce/goods or lost a job		
14.	Had property taken away		
15.	Abandoned by spouse/partner		
16.	Abandoned by family/sent away to the village		
17.	Teased or sworn at		
18.	Lost respect/standing within the family and/or community		
19.	Gossiped about		
20.	No longer visited, or visited less frequently by family and friends		
21.	Visitors increase to “check them out.”		
22.	Isolated within the household		

### Section 4

10. Are there people you personally know who have either disclosed their HIV-positive

status directly to you or publicly in the last 12 months? For example, a family member, friend, neighbour, church member, or work colleague.

1	Yes	
2	No	

11. In your community, what are the primary way people know if someone has HIV? (Tick your choice)

9.	The person discloses his/her status.	Tick
10.	From general rumours/gossip.	
11.	From the HIV-positive person's family.	
12.	From the HIV-positive person's employer.	
13.	From the HIV-positive person's friends/neighbors.	
14.	From the health centre/health care worker where the person got tested.	
15.	The person looks ill and has lost a lot of weight.	
16.	Other (specify).....	

## APPENDIX 3: CONSENT TO PARTICIPATE IN RESEARCH



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**Title:** The influence of leadership on stigma towards People Living with HIV (PLHIV) in Kraaifontein.

You are being asked to participate in a research conducted by Kumbirai Mapiye from the **Africa Centre for HIV and AIDS Management** at Stellenbosch University as part of her research for her MPhil in HIV and AIDS Management. This will contribute to the results of her thesis.

### A) For Community Members

You were selected as a possible participant in this research because you are a community member of Kraaifontein and you are aware that HIV is a problem in the community. It is believed that you will be able to give your honest views about the disease.

### B) For Leaders

You have been selected because you have influence in the community and you are aware of the problems the community faces because of HIV. Your contributions will help us come up with ways of equipping leadership to help reduce the spread of HIV in the community.

## 1. PURPOSE OF THE RESEARCH

To establish why leadership in the community address HIV issues the way they do in order to provide insights to help reduce stigma.

## 2. PROCEDURES

If you volunteer to participate in this research, we would ask you to do the following things:

### A) For community members

You will complete a simple questionnaire and you will not be required to write your name on it. The questionnaire might require thirty minutes of your time on average and you can hand it over to the researcher who gave it to you. You can answer those questions that you are able to by selecting the best suitable answer.

**B) For leaders**

If you volunteer to participate in this research, we would ask you to do the following things:

An appointment will be made to conduct an interview at a place that is convenient, if you don't have a preferred venue, then the Kraaifontein Library will be used. The interview will be recorded but you don't have to disclose your name. The interview might take approximately one hour of your time.

### **3. POTENTIAL RISKS AND DISCOMFORTS**

**A) For community members**

Questionnaires will be completed and there is no link whatsoever to the identity of the participant. The questionnaire will be completed in the presence of the researcher so that any misunderstandings will be cleared. Since the topic is on HIV there might be some questions that you may not feel comfortable to answer, in that case you welcome to not answer the question. Furthermore, it is important to note that the information obtained from these questionnaires is confidential and only the researcher will have access to it. If there is need for further discussion on the topic, that will be accommodated.

**B) For leaders**

An interview will be conducted and recorded. It is important to know that there will be no link to identification whatsoever. The information is only for the researcher and this project and will not be used for anything else. The recordings will be kept very safe under lock. There may be some questions that you may not be prepared to answer. Please indicate this to the researcher and you will be able to move to the next question.

### **4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

Leaders as well as the community at large could benefit from this research. This research will focus on the leaders and their followers in Kraaifontein and the way they address HIV. Findings recommendations will be made. The community could benefit from this research as the problem of HIV-related stigma will be highlighted and ways of reducing stigma will be

discussed. The community could benefit from their leaders' view on HIV issues as this research seeks to establish best ways of impacting stigma in Kraaifontein.

## **5. PAYMENT FOR PARTICIPATION**

No payment will be received for participation in the research.

## **6. CONFIDENTIALITY**

Any information that is obtained in connection with this research and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

A) For community members

Confidentiality will be maintained through the completion of anonymous questionnaires. Hard copies of questionnaires will be kept in a secure place when not being used. The data will be destroyed once the project is finished.

B) For leaders

Interviews conducted will be strictly confidential. The recorded information will be kept under lock and key for safety reasons. No name shall be disclosed. Only the researcher will have the right to listen to the recordings.

## **7. PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this research or not. If you volunteer to be in this research, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the research. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

## **8. IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact Kumbirai Mapiye (Researcher): 084 028 2197, [kumbiemap@yahoo.com](mailto:kumbiemap@yahoo.com) or Caroline Wills (Supervisor): 082 293 4032, [carolinew@iafrica.com](mailto:carolinew@iafrica.com).

## 9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

### SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to ..... by .....in English and I am in good command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this research/I hereby consent that the subject/participant may participate in this research. I have been given a copy of this form.

\_\_\_\_\_

Name of Subject/Participant

### SIGNATURE OF RESEARCHER

I declare that I explained the information given in this document to \_\_\_\_\_ and/or his/her representative \_\_\_\_\_ [*name of the representative*]. He/she was encouraged and given ample time to ask me any questions. This conversation was conducted in *Afrikaans/\*English/\*Xhosa/\*Other* and *no translator was used/this conversation was translated into* \_\_\_\_\_ by \_\_\_\_\_].

\_\_\_\_\_

Signature of Researcher



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## Approval Notice

### Stipulated documents/requirements

04-Sep-2013  
MAPIYE, Kumbirai

**Proposal #: DESC\_Mapiye**

**Title: The influence of leadership on stigma towards People Living with HIV/AIDS (PLWHA)**

Dear Mrs Kumbirai MAPIYE,

Your **Stipulated documents/requirements** received on **04-Sep-2013**, was reviewed by members of the **Research Ethics Committee: Human Research (Humanities)** via Expedited review procedures on **04-Sep-2013** and was approved.  
Sincerely,

Susara Oberholzer  
REC Coordinator  
Research Ethics Committee: Human Research (Humanities)